

DESSH PATIENT REGISTRY



—● www.dessh.org ●—





What is a Patient Registry?

A registry is a collection of information about individuals, usually focused around a specific diagnosis or condition.

- A patient registry platform is a means to easily collect, access and share patient data with doctors, researchers or drug developers to fuel progress within and across rare diseases.



Why a Patient Registry?

- Families will be able to contribute information crucial for scientific researchers to access and use to push the science forward and eventually develop treatments
- Partnering with Rare -X
 - “Patients’ Data Powering Progress”



Data from each patient’s medical history, genome, and other sources are critical to disease understanding, diagnosis, treatment, and the development of future medicines and cures.



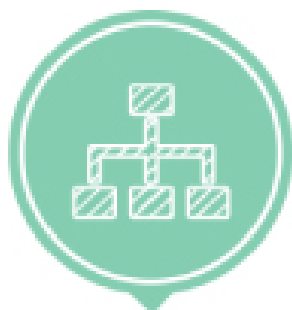
Solving for



Removing critical BARRIERS
affecting cost and access to
reliable and comprehensive
patient data



The data
exists, but
is captive
within a
silo



The data
may exist,
but not in
a useful
form



The data
doesn't yet
exist

Partnering with RARE-X

- RARE-X equips patients to share their data with global researchers, clinicians, and drug developers
- Patient -owned and compliant with all applicable national, international, and state -level privacy laws
- No cost to patients, patient advocacy groups or scientific researchers



Our Patient Registry

- Widespread participation by patients will also empower patients and caregivers during medical appointments by providing data visualizations useful for doctors
- Spanish translation of registry forms and surveys are currently being completed and will also launch soon
- Portuguese and French are also in development





Patient Registry Launch

Launch Fall 2023 !

- Your participation is crucial
- More participation = more data available for scientific research





Stay Tuned!

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